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Study highlights benefits of end-of-life conversations for patients, caregivers

BOSTON--Despite the long-held belief by many doctors that discussing end-of-life issues with patients increases the patients' emotional distress, such conversations can actually lead to improved quality of life -- both for patients and their loved ones, Dana-Farber Cancer Institute researchers and colleagues have found.

In a study published in the Oct. 8 issue of the *Journal of the American Medical Association*, investigators show that patients who reported having end-of-life discussions with their physicians did not feel more depressed, worried, or sad than those who did not. Patients who recalled such talks were more likely to accept that their illness was terminal and prefer comfort care over life-extending therapies. They received less aggressive medical treatment, such as resuscitation or admission to an intensive care unit, and they were more apt to enroll earlier in hospice programs.

More aggressive medical care, which can cause upsetting side effects and hamper communication with loved ones, was associated with worse patient quality of life and worse adjustment by patients' bereaved caregivers.

"Overall, patients who received less aggressive care at the end of life were thought to have better quality of life by their family members and other informal caregivers," says first author Alexi Wright, MD, a hematology-oncology fellow at Dana-Farber and a research scholar in Dana-Farber's Center for Psycho-Oncology and Palliative Care Research.

Particularly striking to Wright was the impact of patients' end-of-life experiences on their loved one's ability to cope with their losses. For example, individuals whose loved ones died in an ICU were three times more likely to develop a major depressive disorder than informal caregivers whose loved ones didn't receive such intensive care.

"Our results suggest that end-of-life discussions may have cascading benefits for patients and their caregivers," the authors note. Adds Wright, "The way people die has a profound impact on the way their loved ones live on afterwards."

End-of-life conversations allow dying individuals to express wishes for the medical care they want to receive. However, these talks require facing their mortality and the limitations of treatments; about 20 percent of patients don't want to discuss death, according to Wright.

"This study extends our understanding of the end-of-life experience," says senior author Holly Prigerson, PhD, study principal investigator and director of Dana-Farber's Center for Psycho-Oncology and Palliative Care Research. "To the best of our knowledge, it is the first to show how care received affects the dying patient's quality of life, and the first to show that a



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patient's health care and quality of life near death significantly influence the adjustment of his or her bereaved survivors."

The analysis was based on interviews with 332 patients and their caregivers at seven different outpatient sites in Connecticut, Texas, and Massachusetts, including Dana-Farber. After a patient died, investigators reviewed his/her medical record and interviewed the informal caregivers (such as spouses or adult children).

These patients were part of Coping with Cancer, a six-year longitudinal study of more than 600 adult terminally ill cancer patients and their caregivers recruited between 2002 and 2008. Participants tended to be younger, female, uninsured, and a member of an ethnic minority group than the population at large.

Preliminary results were announced this past June during the American Society of Clinical Oncology's annual meeting.

Wright hopes the findings will not only spark additional research on communication at life's end but encourage more physicians to be open with their dying patients. "I still take a deep breath before I start an end-of-life conversation," says Wright, who sees patients with gastrointestinal and other cancers. "We all wish we had different answers and better news, but it's important for us to be both frank and empathetic to give patients and their families a chance to prepare for death."

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The study was funded by grants from the National Cancer Institute and the National Institute of Mental Health. Wright received additional support from the Friends of Dana-Farber Cancer Institute and the Program in Cancer Outcomes Research at Massachusetts General Hospital (MGH) in Boston.

The paper's other authors include Tracy Balboni, MD, MPH, Susan Block, MD, Jennifer Mack, MD, MPH, Alaka Ray, MD, Elizabeth Trice, MD, PhD, and Baohui Zhang, MS, all of Dana-Farber; Vicki Jackson, MD, MPH, of MGH and the Harvard Medical School Center for Palliative Care; Susan Mitchell, MD, of the Institute for Aging Research in Roslindale, Mass., and Beth Israel Deaconess Medical Center in Boston; and Paul Maciejewski, PhD, of Brigham and Women's Hospital (BWH) in Boston.

Block and Prigerson are also affiliated with BWH and the Harvard Medical School Center for Palliative Care, Ray is also affiliated with MGH, and Balboni is also with the Harvard Radiation Oncology Program.

Dana-Farber Cancer Institute (www.dana-farber.org) is a principal teaching affiliate of the Harvard Medical School and is among the leading cancer research and care centers in the United States. It is a founding member of the Dana-Farber/Harvard Cancer Center (DF/HCC), designated a comprehensive cancer center by the National Cancer Institute.

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